

Wheelchairs for Children and Youth

safe and practical options that support dignity and community inclusion

This guide was developed by families, physical therapists, an occupational therapist, and a medical supply vendor, to aid decision-making on wheelchairs for children and youth.

Before you choose a wheelchair think about the questions below. Have your notes handy as you go through the process. Include your child/youth in this activity if you can. If that's not possible, think about the answers from their point of view.

NOTES

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| <p>Besides mobility, what else do we want from the wheelchair?</p> <ul style="list-style-type: none"> • Prevent or relieve pain? • Increase independence? • Increase peer/social interactions? • Increase opportunities to participate in the community? | |
| <p>How many hours a day will it be used?</p> | |
| <p>Where will the wheelchair be used? For example:</p> <ul style="list-style-type: none"> • home • school(s) • childcare • friends' homes • airport/travel • community • outdoors | |
| <p>How will I transport this wheelchair? Who else may need to transport it?</p> | |
| <p>What do we need the wheelchair to carry? For example:</p> <ul style="list-style-type: none"> • communication devices • medical equipment • personal supplies or electronics • school books or work items | |
| <p>Who do we know with personal experience that can give us ideas or advice?</p> | |
| <p>Who will help my child learn to use their wheelchair? When and how will this happen?</p> | |

When you have a specific wheelchair in mind, consider these questions:

- How long is this wheelchair likely to meet my child's needs and size? (For example: what your child needs as a preschooler will be different from what they need when they start first grade.)
- How could this wheelchair help my child be a part of the community and make friends? Is it appropriate for their age and size? Do they like the way it looks and moves? Can they customize it the way they like?
- Do we have the information we need to make this decision? Who should we talk to before we order?

Frequently Asked Questions

My child/young adult does not work with a physical or occupational therapist. Who can advise us on what is right for our family?

For insurance to pay for a wheelchair or accessories, a physical or occupational therapist will probably need to provide them with medical information. If your child does not currently have a physical or occupational therapist, talk to your child's doctor about getting established with one.

I've heard getting insurance to pay for wheelchairs can be difficult. What do I need to know?

Keep in mind that it takes months to complete the steps needed to get a wheelchair, so start working on it before you need it. The insurance company needs complete information, including chart notes that address the need for a wheelchair, in order to approve a wheelchair and accessories. In addition to your primary care provider's notes, work with a physical therapist or other medical professional who understands the insurance process. They know what's needed to make a successful claim.

If insurance denies our request for a wheelchair, what are our options?

Your claim has not been denied until you get a *written letter* that tells you so. If your insurance company denies the claim in writing, you should appeal it. Instructions on how to appeal are usually included in the denial. If not, call the insurance company and ask for written instructions on how to appeal. Don't give up with the first denial; think of it as the insurance company needing more information.

If you appeal and are denied again, you can reach out to one of these advocacy programs.

- [Department of Financial Regulation](#) (for commercial or private insurance plans)
- [OHA Ombuds Program](#) or [Governor's Advocacy Office](#) (for Oregon Health Plan)
- [Department of Labor Benefits Advisor](#) (for self-insured plans)

Contact [Oregon Family to Family Health Information Center](#) if you need help with this.

What about borrowing a wheelchair?

There are vendors and programs with wheelchairs you can borrow, lease, or rent. Before going this route, confirm with a physical therapist that the wheelchair is safe and appropriate for your child.

Should we consider a wheelchair that folds?

Both manual and power wheelchairs have foldable models, but there may be some drawbacks. Your child's physical therapist can help you understand the pros and cons of each model.

Even with insurance, the deductible and co-pays are more than we can afford. What programs can help?

[Oregon Family to Family Health Information Center](#) can help you find an organization that might help.

Also check with:

- social workers or care coordinators at your child's hospital or clinic
- your child's service coordinators or case managers, home visiting nurse, or teacher
- your faith community or local service club

Other resources include:

- [Centers for Independent Living warehouses](#)
- [Access Technologies Inc.](#)
- [Regional Programs](#)
- [Wheel to Walk](#)
- [Blanch Fischer Foundation](#)
- [ITAALK](#)
- [Sparrow Clubs](#)

My child is young and will outgrow a wheelchair quickly. Then what?

Most pediatric wheelchairs have the ability to grow as your child grows. Your child will likely be eligible for a new wheelchair either after five years **or** when there is a change in their condition that affects the fit or function. When seeking a replacement chair include chart notes that discuss why the current chair no longer works for your child. If the chair is too small to be safe and effective, get help from your child's PT to apply for a chair that fits. Be aware that insurance won't pay for a new wheelchair when there are changes like starting school, moving to a new home, getting a different car, etc. Do your best to plan for those sorts of changes.

How do I choose a vendor?

Look for a vendor in your region who is experienced with wheelchairs for children and young adults. Ask opinions from parents and professionals who have worked with the vendor, and read online reviews. You want a vendor that responds promptly to questions and repair calls. Your [Oregon Family Network](#) may have recommendations.

How long will a wheelchair last? What can I do to preserve its lifetime?

Most chairs have separate warranties for batteries, frames, and accessories. With care, many chairs will last until your child outgrows them. You can extend their life with the following:

- Clean and maintain regularly. There are journals and apps that can help you track this.
- Inspect quickly for loose parts or wear and tear when getting it in or out of a vehicle.
- Secure properly when traveling.

Will I need to buy a new car or van to fit a wheelchair?

Maybe. Before shopping for a new vehicle, ask the vendor for the wheelchair's size and weight, and how it is secured when driving. Ask them for suggestions about modifying your current vehicle.

Are there resources to help us pay for a new car or van if we need one?

Possibly. If you have one, start by asking your child's Developmental Disabilities or Children's Intensive In-Home Services Coordinator. You can also speak to a care coordinator at your health insurance company or a social worker at the hospital or clinic where your child receives care. Talk to other families, or call the [Oregon Family to Family Health Information Center](#) for ideas. You can also try:

- [Access technologies on-line Marketplace](#)
- [National Mobility Equipment Dealers Association funding page.](#)
- [Steelman Family Foundation](#)
- [Special Kids Foundation](#)

Can we insure the wheelchair?

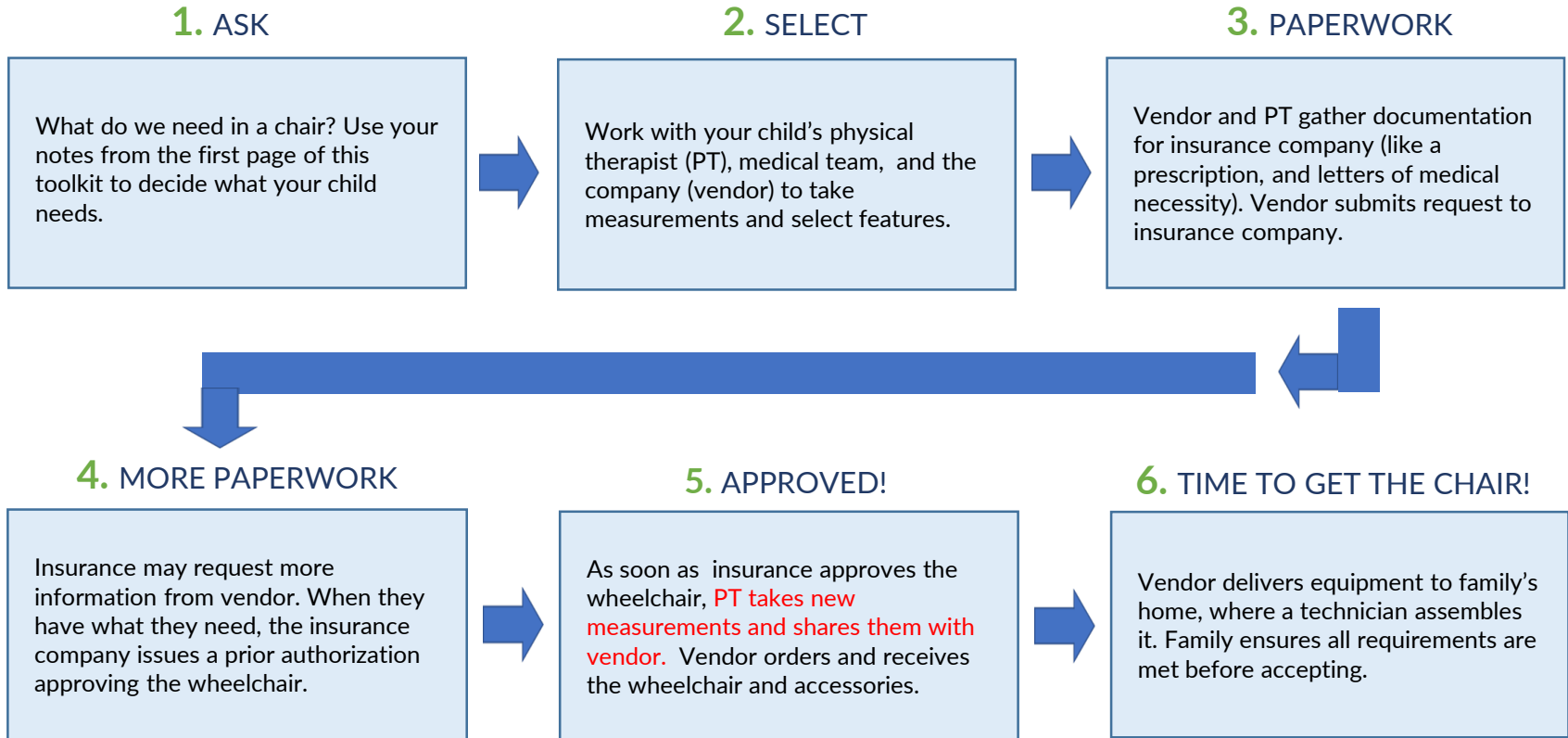
Yes. If you have homeowner's or renter's insurance, you can add it to your policy. Ask your vendor about warranty programs as well.

TIPS from families

- Make sure your child is measured right before the final order is placed.
- If you are given spare parts by a vendor, ask for the manual that shows what the parts are for and how to use them.
- Take videos when the vendor demonstrates its features for future reference.
- Take photos to show therapists and vendors trouble spots, such as where a wheelchair rubs or puts pressure on your child's body.
- Don't use borrowed equipment unless you know it is safe for your child to use.
- Check out [Go Baby Go](#) for ride-on cars for young children. They don't substitute for a wheelchair, but they are a fun option for your child and give them one kind of mobility.
- Buy a back-up battery.
- After narrowing down your options with the PT, ask the vendor for a trial period before ordering.

This toolkit was created by family members of children who use wheelchairs, and professionals who work with them. We gratefully acknowledge the following individuals and organizations: Katherine Breithaupt, Joel Cowley, David Downing, Britta Gurgel, Amanda Hvass, Tawnya Langston, Margaret Maes, Leslie Rodgers, Yecenia Rodriguez, OHSU's Child Development and Rehabilitation Center, Central Oregon Disability Support Network, Hands and Voices of Oregon, NuMotion, and Sunrise Medical Company.

Rolling through the process







PRO TIPS

- At each step, follow up after a couple weeks if you haven't heard that things are progressing.
- To ensure a good fit, as soon as the vendor tells you approval is close, make an appointment with the PT to take new measurements of your child.

Pediatric Wheelchair Examples

(for children only)

| <p>SAMPLE PHOTOS →</p> <p>These photos do not represent particular brands or models, nor is this an inclusive list. There are many options available. Your child's Physical Therapist can help you choose the best option..</p> | <p>Standard</p>  | <p>Manual</p>  | <p>Tilt in space</p>  | <p>Power/Electric</p>  |
|--|--|---|---|--|
| Chair weight | 20-30 pounds | 14-25 pounds | 40-80 pounds | 60-270 pounds |
| Weight capacity | 165 pounds | 165 pounds | 165 pounds | 165 pounds |
| Folding | Yes | Removable wheels, sometimes fold | Sometimes folds | Rarely folds |
| Postural and pelvic/chest supports | Sometimes customizable | Customizable | Customizable | Customizable |
| For easier transfer | Height is standard, some armrests move | Can order to match child's height, armrests move | Armrests move, some seats tilt | Some have power assisted transfers, armrests move |
| Tilt/recline available | Sometimes | No | Yes | Yes |
| Wheel type | Front wheels small, back wheels may be small or large | Two small wheels in front, larger wheels in back for self-propulsions | Two front casters, back wheels, wide medium sized | Typically 6 wheels in a few different configurations |
| Accessory storage | No | No | Can be added | Yes, customizable |
| Growth potential | No | Yes | Yes | Yes |

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